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Giving Effective and Timely Hospice Education to Lessen Participant Stress (GET HELPS)

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Abstract

In 2022, 1.72 million people chose to use hospice as their end-of life care. This is a 6.8% increase from 2019, and the number of patients who choose to use hospice is increasing (Summers, 2022). Medicare defines four levels of hospice care, two of which take place within the home of the patient- routine home care, continuous home care, general inpatient care, and respite care. When hospice care is provided in the home, nursing staff cannot always be present, and much of the care responsibility falls to the patient and their informal care team (referred to henceforth as PCT). It is important for the PCT to understand what to do in a variety of situations, and it is easy for the responsibility to become overwhelming. This can be seen in the satisfaction ratings from a hospice care program in the Concord, New Hampshire, through a Hospital Consumer Assessment of Providers and Systems (HCAHPS) survey. The PCT reports of satisfaction with the education provided fall below the state and national average. When talking to the PCTs in their homes, they reported stress regarding a lack of effective education. The aim of this quality improvement (QI) study was to decrease levels of stress reported by the PCT by combining the information from the hospice program's admission packet and other approved handouts, while standardizing the verbiage through a Flesch-Kincaid readability scale to an eighth-grade reading level. Pre-survey perceived stress scores averaged 22.97 on a modified Perceived-Stress Scale, and the mean of the post-survey averaged 19.38, suggesting a decrease in stress experienced by the PCT when provided with simplified, effective, and timely education.

Keywords: hospice, home hospice, readability, perceived-stress score, visiting nurse, caregiver burnout

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Giving Effective and Timely Hospice Education to Lessen Participant Stress (GET HELPS)

In New Hampshire, two organizations work hand in hand to provide high quality end-of-life care to patient and informal caregiver teams (PCT) across four counties in New Hampshire, including Merrimack, Hillsborough, Carroll, and Belknap County. One of these is a hospital facility, and the other is a community-based, not-for-profit organization that offers home care, hospice, palliative care, pediatric and maternal child health services, and wellness programming. This is a program that allows patients of any background to receive the comfort and care they need during the end of life. The staff provides comfort care (not treatment) through symptom and pain management to ease the final transition of their patients while caring for the families that are affected by the loss of their family member. The facility delivers the same care in the patient's home setting, providing a registered nurse (RN) visit every two weeks, a licensed nursing assistant (LNA) visit multiple times a week, and any adjunct therapies that are approved of for the comfort of the patient. Hospice care is covered by Medicare Part A, but Medicaid and other private insurers may also cover the expenses, leaving the patient with little to no payments pertaining to care at all. Unfortunately, not everyone knows this, or what hospice truly is.

Problem Description

When most people hear the word "hospice" it triggers a certain level of unease, a feeling of discomfort, and an impending sense of imminent death. Shalev et al. collected quotes from participants, many of whom reported "hospice is only about death" and "hospice is seen as giving up" (2018). In this same study, out of 664 respondents, 60% were able to label hospice care as end-of-life care, yet only 5% were able to note hospice care as a patient and family support, and less than 2% noted it focused on quality-of-life improvement (Shalev et al., 2018). The misconceptions and stigma against hospice seen in this and other studies could be attributed

to a lack of public and patient education regarding hospice care. Unfortunately, this lack of education has also left the two facilities mentioned with lower ratings with their patients and families than what is desired.

According to Medicare's Hospital Compare website, the hospice program has a 73% survey rating for training the family to care for the patient, whereas New Hampshire has a 75% average, and the national average is 76% (HCAHPS, n.d.). On multiple occasions during the current semester, home hospice PCTs have verbally reported feeling unprepared and overwhelmed with the information that has been given to them from the home care team. Many did not know what hospice was before admission, and even those that did were concerned about the care they would be providing. PCTs must be educated in a way that is both understandable and brief, particularly when they are in a stressed and vulnerable state. The PCTs included were current residents of New Hampshire, a state that has the highest literacy rate in the United States (88.5%) and is predominantly Caucasian (92.8%), which made findings difficult to generalize across any other populations (United States Census Bureau, 2022). In New Hampshire, the education index, an average showing educational attainment levels of a population by calculating the mean years of schooling and the expected years of schooling, ranks each of the ten counties based off their educational attainment. The maximum number that can be calculated is 15 years, and each county falls short, including Merrimack at 14.01 years, Hillsborough at 14 years, Carroll at 13.98 years, and Belknap at 13.77 years (USA.com, 2023). Out of the New Hampshire counties, this places the counties the facility serves at 3rd, 4th, 5th, and 8th place respectively. While the literacy rate in New Hampshire may be high, health literacy becomes a topic of interest for this vulnerable population. Often, PCTs are left with concerns over what actions to take during home hospice care, worried they are not providing the best care to themselves or

their family members while clinical staff is absent. This scholarly project aims to improve home hospice education for the PCT through a simplified educational packet. By providing an improved health literacy packet at an eighth-grade reading level, it was expected that PCTs would report improved knowledge of home hospice care, increased comfort providing that care, and report lower levels of stress.

Available Knowledge

For this research, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE were utilized. CINAHL has a large collection of nursing, allied health, biomedicine, and healthcare literature dating back to the 1940s. MEDLINE is the National Library of Medicine's bibliographic database and has been in operation since the 1960s, focusing on biomedicine. Both are user-friendly resources that can be utilized to search for relevant articles and essays through basic and advanced filtering systems. Both search engines are supported by EbscoHost and can be searched simultaneously on one webpage.

Two key search fields were used for this review. The first contained "hospice OR end-of-life care OR terminal care". The second search field contained "education OR patient education OR caregiver education OR patient stress". This resulted in over 500 search results before inclusion and exclusion criteria were introduced. To narrow the initial screening to a more manageable number, the results were limited to full text only, peer reviewed studies that focused on English speaking adults over the age of 19 in the USA. This reduced the number of results to 103. Of the 103 screened, six were excluded due to an error in the webpage. The titles and abstracts for the 97 articles were then screened further, including geographic location, participant ages, English language, and relevance to topic to exclude any the search algorithm missed. 24 were excluded because they were outside of the USA, 11 were excluded because they included

results on the pediatric hospice population, and 53 were not related to research, focusing more heavily on clinician education.

Critical Evaluation of Research

The articles that passed the screening process were ranked using Melnyk's Level of Evidence, a quality measurement guide with seven quality levels. Level one is the highest level of evidence, focusing on systematic reviews and meta-analyses of randomized controlled trials (RCTs). The level of evidence then decreases with each level until the seventh level, which focuses on evidence from opinion and expert committee reports. There were nine total articles that were included in the review of available knowledge, including two systematic reviews.

Ector, Hermens, and Blijlevens (2020)

This level one systematic review was made up of systematic reviews from 2003 till 2020 to find possible gaps in patient information, education, and comprehension regarding hospice care. They also sought to determine what interventions would work best to fill those educational gaps for hospice patients and caregivers. The systematic reviews were compared before the information was filed to create a comprehensive report of what interventions may work best with various populations. They found adequate eHealth interventions and education were the key to improving patient quality of life, medication adherence, and mental health wellbeing (Ector et al., 2020).

The limitations for this systematic review were that the barriers of information exchange were not well explained, and the readability of health literacy results was not well documented, though the authors believe adjusting the comprehension level is likely the simplest intervention. The biggest strength of this review is how the results can be easily generalized across various cancer patients due to the large heterogeneous sample sizes of each article included, allowing for

speculation of ideas for further research that can be used across a wide variety of peoples. As cancer makes up 31% of all hospice diagnoses, the number of patients and caregivers that feel they need more information to adequately care for themselves or their loved ones needs to be resolved.

Lassell, Moreines, Luebke, Bhatti, Pain, Brody, and Luth (2022)

This level one article was a systematic review with a purpose of understanding who the primary targets of hospice education were, what types of interventions had been developed, what the outcomes were, and what interventions have had the most evidence. The systematic review included five databases and through inclusion and exclusion criteria, focused on 10 articles that focused on people living with dementia (PLWD), their caretakers, and clinical staff for home hospice care. They concluded clinical education and training are the most promising interventions to improve self-efficacy and caregiver ability, but more research must be done before a standardized intervention can be found (Lassell et al., 2022).

Limitations included the fact that some studies may have been overlooked due to the criteria, and that by using CONSORT to evaluate the study's quality, bias may have been introduced to the to the assessment of nonrandomized studies. This was specifically focused on patients living with dementia, so it is not applicable to other hospice cases, though dementia makes up 10% of all hospice diagnoses. The authors created this systematic review to incorporate many different hospice care settings, and though specific interventions had not been found, they highlighted the need for long term, sustainable interventions.

Chi, Demiris, Pike, Washington, and Oliver (2018)

This level two review was a theory driven, deductive content analysis of data from a recently completed five-year long RCT. The authors also analyzed other RCTs and compared

findings. The goal of this study was to identify challenges in pain management for informal caregivers in the home hospice setting. They found four major themes, including caregiver centric issues, caregiver medication concerns with skills and knowledge, communication and teamwork issues, and individualized patient centric issues (Chi et al., 2018).

The limitation of this study was a small, homogeneous sample size that was selected from a single geographic area, so the findings cannot be generalized. The findings of this study seem to influence each other; by managing a patient's pain, the family caregiver is less burdened, but when pain is not managed well, the burden increases on the caregiver and patient. They interviewed 15 family caregivers of patients from Washington state, then analyzed them based off Kelley's "Informal Hospice Caregiver Pain Management Concerns" framework (Chi et al., 2018). They then coded the interviews line by line assigning sentences to themes. As mentioned above, they found four major themes, caregiver centric issues, caregiver's medication skills and knowledge, communication and teamwork issues, and patient centric issues.

El-Jawahri, Traeger, Greer, Vanbenschoten, Markovitz, Cashavelly, and Tata (2020)

This level two study was a single RCT of a video educational tool as compared to a verbal description of hospice care to 150 patients with terminal cancer and their caretakers. The goal was to educate patients and caretakers to determine the effectiveness of video education on hospice preferences, including knowledge and perceptions of hospice care. They found no difference between the video intervention and verbal control group regarding hospice preference, but 85% of the video group did report greater knowledge regarding hospice care. Among the participants, 85% of the video group utilized hospice care, where only 63% of the control group used hospice (El-Jawahri et al., 2020).

One limitation of this study was that it was carried out at one location, limiting its generalizability. Another limitation was the research assistants may have been biased because they were not blinded to the randomization, though they did use blinded research assistants to collect the data. They unfortunately did not have the data to compare differences between participants and nonparticipants, and they did not assess any prior experience the participants may have had with hospice care. A strength of the authors is they realized a possible reason for having high baseline preference for hospice care was that they had gathered their participants from an academic center that was already highly integrated with a palliative care center. They believe the video intervention better informed participants and enhanced their ability to ask the right questions to their clinicians, resulting in better hospice outcomes.

Gregory and Gellis (2020)

This level two RCT pilot study focused on 43 hospice caregivers from home hospice admissions. The purpose was to examine informal caregiver problem solving efficacy and its effect on quality of life and depressive symptoms compared to usual care and the caregiver education intervention group. They found a slight increase in depression, though it was not significant, but they did find how low-cost behavioral interventions could increase coping and quality of life for caregivers, such as problem-solving therapy and education, resulting in better outcomes for patients.

Limitations in this pilot study were a small sample size, and a homogeneous group that was mostly female and Caucasian. This group had low scores of depression at baseline, and it is believed the time period for the intervention was too short to show significant changes. The final limitation was that the study was only carried out by a single person due to availability issues.

One strength was that it was randomized through a computerized allocation program, and this sample only included home hospice patients and caregivers.

Schulman-Green, Linsky, Blatt, Jeuland, Kapo, and Jeon (2023)

This level two study was a single center, parallel arm pilot RCT of informal caretakers that incorporated a systematic review. The purpose was to test a psycho-educational intervention to improve patient and informal caregiver health literacy, understanding, goal communication, and adherence. They found participants in the intervention group showed increased health literacy and better engagement in symptom management. They also found the intervention decreased uncertainty for patients and caregivers. 74.3% of participants knew of hospice care, though they were made uncomfortable by it, and would have preferred it to be talked about in a brief, hopeful manner (Schulman-Green et al., 2023).

Again, a limitation for this study was a small sample size from one geographic location, which limits generalizability. Since this study had an evaluation at one month and a repeat evaluation at three months, it is possible recall bias could have affected the second evaluation. Some participants also reported knowing certain topics, and so they did not feel the need to read all the modules. The study also did not assess the utilization of palliative care or hospice care through chart reviews. Something the authors did well was ask the participants about what they felt were strengths, weaknesses, and limitations of the “Caregiver’s Guide”. Some spoke of how it helped them talk about the future, others mentioned it helped them communicate more effectively with their clinicians to uncover more options and understand the why’s and how’s of being a caregiver to their patient.

Abedini, Downey, Engelberg, Curtis, and Sharma (2022)

This level four cohort study used logistic regression models with a restricted maximum likelihood estimation to better analyze the outcomes of adults with serious illnesses receiving EoL care (Abedini et al., 2022). They studied the difference in outcomes between English language proficient patients and patients that had a limited English proficiency (LEP). It was found patients with LEP had higher percentages of Emergency Department visits (33% versus 20%), inpatient hospitalizations (55% versus 46%), and intensive care unit admissions (31% versus 24%), while also having a lower percentage of consultations and advanced care planning documents (Abedini et al., 2022). This study had several limitations, such as unknown data on whether goals of care were prompted by clinicians, the quality of those discussions and assessments, and the undocumented use of interpreters for those LEP patients. They were also unable to collect information on the patient's EoL care to assess whether their preferences were met and were goal concordant or not. The group for LEP patients was highly heterogeneous through culture, religious beliefs, and values, but the participants were only from a small health system and geographic region, limiting generalizability. The authors found there is less hospice utilization in LEP patients, resulting in more hospitalizations within the last six months of life. The high intensity care at the EoL from an inpatient unit may decrease quality of life by prolonging patient suffering. By providing information that is easier to decipher, these patients are more likely to understand their options and receive quality care.

Shaley, Phongtankuel, Kozlov, Shen, Adelman, and Reid (2018)

This was a level six study where phone interviews were conducted to understand what adults in community living thought of hospice care. Eight hundred participants were interviewed to determine awareness, misconception, and receptivity toward hospice care. Sixty percent of participants knew it had to do with EoL care, 17% did not know what hospice care meant, and

only 3% knew it provided symptom management, suggesting a lack of hospice education and public awareness (Shalev et al., 2018). Limitations of this study include a lack of follow up questions to participants where they may have elaborated further had they been asked, and that open ended questions may not have captured the person's full awareness of the situations being discussed. While the sample size was large, it was only from one location in New York state, and all other demographics of the patients were behind a paywall, other than the fact that all patients were over 18 years old. The authors determined 10 key components of hospice care, being that it is delivered at EoL, provides care to both patients and families, provides symptom management, offers spiritual and social supports, assists with goals of care, works through an interdisciplinary group, is comfort care, offers bereavement to the families, affirms life and normalizes death, and seeks to improve quality of life (Shalev et al., 2018).

Shalev, Phongtankuel, Reid, Czaja, Dignam, Bagn, Newmark, Prigerson, Teresj, and Adelman (2019)

This second study by Shalev and colleagues is also a level six study, using semi-structured phone interviews to identify what information informal caregivers felt they needed to provide best care to their family members. This study determined three unmet information categories, including general hospice information, what the caregiver should expect from EoL care, and support resources available from the hospice staff. The authors also found upon giving the caregivers a series of educational booklets, 98% of them reported it as helpful (Shalev et al., 2019). Similar to the prior study by this author, open ended questions were a limitation that may have resulted in answers that lacked specific awareness. These participants were selected from a single hospice organization in an urban setting but had a low response rate. The authors considered this last limitation to be a strength as well, because the low response rate may have

been due to the recent passing of their loved one, but they believe this was the best time to get responses so they may better assess the needs of the family following the patient's discharge from home hospice.

Evidence Synthesis

To summarize these results, research figures suggested a lack of timely and cohesive information result in lower quality of life scores for both patients and informal caregivers. By educating both patient and caregivers earlier in the illness process, earlier admissions to hospice care can be arranged, resulting in better quality advanced care planning, less high-quality hospitalizations that may prolong suffering, and increased satisfaction in decision making (Ector et al., 2020). Those living with advanced illness tended to avoid talking about death and the dying process because it made them uncomfortable and fearful for the future, but with information interventions to correct misconceptions, they were more likely to utilize hospice care in a timely manner, allowing them to be comfortable at the time of their death (El-Jawahri et al., 2020). This also encouraged self-efficacy in care, both by patients that are physically able to do so and their informal caretakers in the home setting (Lassell et al., 2022). By reviewing previous peer-reviewed studies, frameworks and major themes can be utilized to continue research to better the health outcomes of patients and caregivers (Chi et al., 2018). The interventions need not be expensive, so long as they are delivered in a timely manner through an interdisciplinary team (Gregory & Gellis, 2020).

Hospice educative opportunities are not yet well realized, but through community outreach and interview processes, researchers may begin to better understand the areas that need a deeper focus, such as what to expect at the EoL, the supports hospice provides, and general information that is taken for granted by clinical staff (Shalev et al., 2019). To best provide

educative interventions, it may be pertinent to provide information at a comprehensive level that is understandable even to patients with a LEP (Abedini et al., 2022). Even for patients that are proficient in English, it is helpful to improve the health literacy to those in stressful situations, as it may increase confidence and self-efficacy while decreasing uncertainty and stress (Schulman-Green et al., 2023). Through each study, education was brought forth as an intervention that could change the way families and patients view and utilize hospice care.

Rationale

Using the Plan, Do, Study, Act (PDSA) framework, this quality improvement (QI) project focused on improving self-efficacy among participants through education to improve care and decrease feelings of stress. This process included informal PCT interviews, transitioning the results from their reports into an educative physical medium, reviewing the reported stress scores through pre- and post-surveys, and building on those results to create a plan of action for following studies. Albert Bandura's theory of self-efficacy leans towards the idea that "competence and capability links to action and practice" (Granat et al., (2022)). The participants were interviewed before and after reading the packet to assess for improvement in providing and understanding care. The theory was that by providing accessible and easy to understand information, the PCT's perceptions of their own ability to provide care will improve, resulting in higher levels of coping, resilience, and satisfaction, while resulting in decreased levels of education and situation-based stress (Gallagher, 2012).

Specific Aims

The specific aim of this QI project was based off evidence-based practice and direct observation of PCTs. The aim was to increase the maintenance and comprehension of hospice education of home health practices for PCTs of the hospice program through an improved health

literacy packet starting May 25th, 2023, and ending in July of 2023. The goal was to decrease reported stress by 30%. The process began with identifying what causes the most stress for patients and where they feel least supported and ended with disseminating educative terminology and techniques that are easy for most to understand and carry out. The goal was to lessen patient stress and increase patient quality-of-life by providing an educational package containing step-by-step information with images, medication explanations, and contact information in case of questions or concerns. The effectiveness of the intervention can be measured through patient response through pre- and post-surveys. The participants (n = 7) took part in this QI project by scanning the Qualtrics™ survey QR code in the beginning and end of the folder. Expected outcomes included decreased reports of caregiver and patient stress through a modified Perceived-Stress Score, and increased patient satisfaction, more positive illness perceptions, higher quality-of-life, and more effective pain management through participant reporting (Ector et al., 2020).

Methods

Context

Hospice is a form of EoL care that provides comfort care as opposed to curative treatment. It is a free care resource that is covered by Medicare Part A, yet many potential hospice patients and caregivers know little about the benefits, resulting in confusion, stress, and underutilization. For patients and caretakers that are utilizing home hospice, there are often unmet informational needs that result in undermedication that can result in discomfort, stress, possible errors in care, and a lower quality-of-life (Ector et al., 2020). The population studied in this project were the PCTs that are admitted to home hospice through a community-based organization in New Hampshire. The home hospice program allows patients of any background

to receive comfort, care, and respect within their homes as the time of death draws near, but surveys have shown former PCT satisfaction with their education is lower than the state and national average.

Cost-Benefit Analysis

The direct costs of this project were low due to a small participant size and material costs. The goal was to give one packet to each PCT, a packet consisting of 9 pieces of paper, 1 staple, and the ink used to print instructions, guides, and images. The goal was to provide the intervention to 25 PCTs, using 200 pieces of paper, and 400 pages worth of ink if the packet is double sided. According to an online store, one 300 sheet package of premium color copy paper is \$12.25, and the amount of ink needed to cover that is likely three cartridges. The ink was the most expensive part of this project, likely coming out to \$80. Combined without considering items like gas used to get to participant homes and personal hours creating and improving the packet, this project costs a total of \$92.25.

The opportunity costs, or the potential benefits missed out on by stakeholders (the PCTs) by choosing one option over another, of this project are the \$3.5 billion dollars in savings hospice care contributes for Medicare (NHPCO Staff, 2023). A study carried out by the National Hospice and Palliative Care Organization (2023) found EoL expenditures are lower for patients who are admitted into hospice care earlier, and even if the patient is on hospice for over six months, the Medicare spending was still 11% less than if the patients did not use hospice at all. Most patients on hospice do not follow through with intensive care visits or expensive procedures due to education on comfort versus curative treatment, but by providing education on reducing fall risks and maintaining a safe environment, expensive hospital visits regarding broken bones and lacerations that would not be covered by Medicare could be avoided

(Overland, 2014). Another opportunity cost would include Hospice House treatment of infections due to inappropriate wound care due to a lack of education or altered mental status due to a lack of medication education, resulting in a general inpatient charge of \$260 per day that is not covered by Medicare. The informational packet is a cost-effective way to improve quality of life for patients and caregivers through education that they may read with the loved one or on their own time.

Interventions

The intervention used in this project was an improved, targeted information packet with a lower readability level to improve understanding in all participants, as well as increase education on home care techniques. Before the intervention was created, participants were interviewed to find what they believe to be areas of unmet informational needs during their admission into home hospice care, and overwhelmingly the answers have been questions on medications in the comfort kit, medication administration, and wound care. Concerns over these items result in participant stress, a lack of self-efficacy, and self-doubt. For this project, the home hospice admission packet from the home hospice program was adjusted by comparing the language and sentence length to an eighth-grade readability level through the Flesch-Kincaid grade level readability formula and the Dale-Chall Readability Formula. The Flesch-Kincaid formula was created in 1948 to produce a grade-level score that calculates a readability score based on average sentence length and average number of syllables per word (Zamanian & Heydari, 2012). The Dale-Chall formula expands upon the Flesch-Kincaid formula by assessing understanding based on the familiarity of words to a fourth-grade reading level, removing difficult or unfamiliar words, further extending the accessibility of information to a larger amount of people (Klare, 1952).

Using these readability formulas and guided by the facility's current admission folder, an intervention was created to provide an improved education packet with the goal of decreasing PCT stress. This packet include education on the comfort kit medications, resources available to the PCT, an introduction to the home hospice team, the benefits of hospice care and how to withdraw should the patient wish to seek further curative treatment, and how to care for the most common wounds when clinical staff is not present, such as pressure sores, weeping edema, and venous ulcers. The professional team involved to create this packet included stakeholder approval from the facility, a registered nurse that specializes in home care, a medical social worker, and feedback from the PCT.

Study of the Interventions

The impact of the intervention was assessed through participant surveys carried out through Qualtrics™, accessed via a QR code on the first page for the pre-survey, and the final page for the post-survey. This opening page also included a brief summary of this project and a participant information sheet that explained the voluntary nature of the intervention. Using Likert Scale questions, the participants took a brief, categorical pre-survey asking whether they are the patient or caretaker followed by a perceived stress test modified for home hospice. After this was done, the participants may read the informational packet at their leisure and upon reading, scan another Qualtrics survey at the end of the packet, completing a post-survey. The post-survey the questions from the modified stress test.

Measures

Stress, through an operational definition, is a natural human response to difficult situations (WHO Staff, 2023). It is a state of worry or mental strain that can be found in any environment, but in the case of this study, it was assumed to be caused by the mental and

emotional burden of role overload. This is the perceived stressor that a person experiences when they feel their workload or work role exceeds personal stressors in their life (Tang & Vandenberghe, 2021). Role overload occurs when an individual is trying to fill multiple roles at one time while lacking the time, resources, and energy to complete them properly, such as an informal caretaker trying to serve as a caretaker, parent, financial provider for the home, and more.

The instrument used for this project to measure the effectiveness of the outcome is a modified Perceived Stress Scale (PSS-10) to reflect the stressors of home hospice care for the PCT. This is a scale created by Cohen, Kamarch, and Mermelstein (1983), and is a classic stress assessment tool for understanding a participant's perceived stress and feelings surrounding a particular time in their lives. Using a five-point scale from zero (never) to four (very often), the participants were asked to self-report how often they have felt a certain way. Permission has been granted by Sheldon Cohen to modify the PSS-10 to make it specifically applicable to home hospice care (Appendix A). This survey was chosen due to its wide use and ability to address how different situations affect a participant and how they experience stress. According to a study from 2019, the unmodified PSS-10 demonstrates adequate internal consistency reliability ($\alpha = .78$), as well as concurrent criterion validity ($p = < .001$) regarding weekly stress (Baik et al., 2019). The authors went on to include a variety of other articles that also reported the scale has good internal consistency reliability and convergent validity regarding measures of physical and mental health, and how it is widely regarded as an appropriate measurement tool (Baik et al., 2019).

Reliability of the modified PSS survey will be tested through Cronbach's alpha coefficient, a statistic that can be used to determine whether a group of survey items consistently

measures the same characteristic (Frost, 2022). Because this survey asked 10 questions on the concept of stress, by assessing them using Cronbach's alpha, the scores on the questions should be similar. If they are indeed similar, the Cronbach's alpha score should be closer to one.

Cronbach's alpha measures the level of similarity of scores on a scale of zero to one. The higher the number, the higher the agreement, and the if the number is low, it shows the set of questions do not reliably measure the same construct (Frost, 2022). Zero indicates no correlation, but many researchers use 0.7 as a benchmark value for this coefficient, meaning values nearer to 0.7 are acceptable, but not ideal, and higher numbers are most favorable for reliability (Frost, 2022).

Validity evaluates whether the survey or test used measures the results they are supposed to measure, in this case, stress experienced by the PCT, as opposed to a separate measure such as anger or grief. Construct validity relates to the accuracy of the deductions drawn from the scores (Frost, 2022). A construct is a complex idea created to understand variables that cannot be observed directly, such as anxiety, stress, and self-esteem. This form of validity confirms whether the test or survey measures the intended construct, in this case, PCT stress. To be valid, the constructs must be convergent and discriminant. Convergent validity shows a specific correlation between measurements and a similar correlation, such as unmet information and stress. To be divergent, measures of characteristics would not connect to one another, such as stress correlating with a high quality of life.

Analysis

To analyze the qualitative survey results, SPSS Statistics was utilized. Regarding categorical data, the participants were asked to identify whether they identify as a man or a woman, what their age group is, their race, and their level of education. This will later be shown in percentages, as well as ratios. Nominal data will be measured through much of the categorical

data, but they were also asked if they had utilized hospice previously. The qualitative information from this survey will be determined from the free text area located at the end of the post-survey. This helped to develop patterns and themes of unmet information for the PCT that they feel would be helpful in providing care and decreasing stress.

Ethical Considerations

The project lead is not an employee of the hospice facility and does not have friends or family under the care of the facility, resulting in no conflicts of interest. As this was an adjunct educational intervention with the hospice program's admission packet, there was no group that does not receive the general education that the program provides. As all the surveys were anonymous, there was no way to identify individual responses. This was a voluntary survey, and the materials for the physical packet cost around \$100 dollars. This intervention to patients will likely decrease PCT stress while improving education, allowing for higher satisfaction ratings in the future. This project proposal was reviewed by the University of New Hampshire Quality Review Committee and deemed exempt from the Institutional Review Board.

Results

The aim of this intervention was to decrease stress experienced by the PCT following admission to home hospice. It was carried out by simplifying the original admission folder for the home hospice program (over 36 pages with multiple smaller pamphlets on differing topics), resulting in a 17-page educational pamphlet containing images and a 14-point text size. This pamphlet was constructed and reviewed by the facility's Security/Privacy Officer and Vice President of Education and Quality. Minor changes were made to the packet following review before it was distributed. Approval faced a three week delay due to an executive taking a leave of absence where they were unable to be contacted, which resulted in the implementation process

beginning later than expected. Before approval, it was instructed that the newer packet be distributed alongside the original admission folder. The printed packet was delivered in person and its purpose was explained during Advanced Illness Management (AIM) meetings in the home setting. The AIM team is unique to this facility, consisting of a registered nurse and a social worker. These two individuals meet with palliative home care patients following a professional care referral to explain what hospice care is and what it would mean for them should they choose to transition. The intervention packet was delivered to individuals upon admission to the service. All surveys were voluntary and not all who received the intervention participated. The pre- and post-surveys were completed through Qualtrics™.

There were seven respondents who completed both surveys ($n = 7$). There were multiple participants who did not complete the post-survey, and they were not counted in the results. Demographic questions included participant age, education status, ethnicity, and previous experience with hospice care. Most respondents were within the age range 51-60 years old (57.1%), with 28.6% being between the ages of 61-70 years old, and 14.3% being 71-80 years old. 100% of participants were white/Caucasian. 71.4% of participants had not had experience with home hospice before, 14.3% graduated high school as the highest level of education, 71.4% had graduated college with an undergraduate degree, and 14.3% had graduated with a post-graduate degree. The demographics can be seen in full detail below in Table 1. The results of the pre-survey and post-survey are shown in Figure 1.

Table 1*Demographics Table*

	<i>n (%)</i>
Age	
50 years or younger	0 (0)
51-60	4 (57.1)
61-70	2 (28.6)
71-80	1 (14.3)
Ethnicity	
Asian	0 (0)
Black or African American	0 (0)
Hispanic or Latino	0 (0)
Middle Eastern or North African	0 (0)
Multiracial or Multiethnic	0 (0)
Native American or Alaskan Native	0 (0)
Native Hawaiian or Pacific Islander	0 (0)
White or Caucasian	7 (100)
Other	0 (0)
Experience with Hospice	
Yes	2 (28.6)
No	5 (71.4)
Education	
Middle School	0 (0)
High school graduate	1 (14.3)
College Graduate	5 (71.4)
Post-Graduate	1 (14.3)

Contextual Elements

Contextual elements that interacted with this intervention included previous experiences with hospice care, the length of time the PCT had been utilizing hospice care prior to the intervention, a person's mental health, financial stressors, and social supports available. A modified Perceived-Stress-Scale (PSS-10) was used to measure the effectiveness of the intervention, each question being ranked 1 to 5 in a Likert scale. Questions 1, 2, 3, 6, 9, and 10 were scored from 1 (Never), 2 (Some of the Time), 3 (Half of the Time), 4 (Most of the Time), and 5 (Always). The scores were inverted for questions 4, 5, 7, and 8, where Never would score

a 5 and Always would score a 1. Results for the surveys can be found in Table 2 and Table 3 below.

Table 2

Pre-Survey Mean, Standard Deviation, and Range

<u>Pre-Survey Likert Questions</u>	<u>M</u>	<u>SD</u>	<u>Range</u>
1. Since admission to home hospice, how often have you been upset because of something that happened unexpectedly?	2.73	0.8997	1-5
2. Since admission to home hospice, how often have you felt that you were unable to control the important things in your life?	2.85	1.0	1-5
3. Since admission to home hospice, how often have you felt nervous and stressed about caring for yourself or your family member?	2.91	1.345	1-5
4. Since admission to home hospice, how often have you felt confident about your ability to handle home-care situations?	2.52	0.534	1-5
5. Since admission to home hospice, how often have you felt that things were going your way with home-care?	2.03	0.690	1-5
6. Since admission to home hospice, how often have you found that you could not cope with the care that you had to provide in addition your current lifestyle?	1.66	0.899	1-5
7. Since admission to home hospice, how often have you been able to effectively control stressors in your life?	2.90	0.816	1-5
8. Since admission to home hospice, how often have you felt that you were on top of time management and providing care?	1.73	0.690	1-5
9. Since admission to home hospice, how often have you been angered because of things that happened that were outside of your control?	2.0	0.899	1-5
10. Since admission to home hospice, how often have you felt difficulties were piling up so high that you could not overcome them?	1.64	1.069	1-5
<u>Total Mean</u>	22.97		

Table 3*Post-Survey Mean, Standard Deviation, and Range*

<u>Post-Survey Likert Questions</u>	<u>M</u>	<u>SD</u>	<u>Range</u>
1. Since admission to home hospice, how often have you been upset because of something that happened unexpectedly?	2.42	0.534	1-5
2. Since admission to home hospice, how often have you felt that you were unable to control the important things in your life?	2.0	0.577	1-5
3. Since admission to home hospice, how often have you felt nervous and stressed about caring for yourself or your family member?	2.28	0.487	1-5
4. Since admission to home hospice, how often have you felt confident about your ability to handle home-care situations?	2.14	0.377	1-5
5. Since admission to home hospice, how often have you felt that things were going your way with home-care?	1.71	0.487	1-5
6. Since admission to home hospice, how often have you found that you could not cope with the care that you had to provide in addition your current lifestyle?	1.71	0.755	1-5
7. Since admission to home hospice, how often have you been able to effectively control stressors in your life?	2.42	0.975	1-5
8. Since admission to home hospice, how often have you felt that you were on top of time management and providing care?	1.71	0.755	1-5
9. Since admission to home hospice, how often have you been angered because of things that happened that were outside of your control?	1.57	0.534	1-5
10. Since admission to home hospice, how often have you felt difficulties were piling up so high that you could not overcome them?	1.42	0.534	1-5
	<u>Total Mean</u>	19.38	

The scores of the pre- and post-surveys revealed a higher stress score before the intervention and a lower score following implementation of the educational packet. Before the intervention, the mean stress score was 22.97, and following the intervention it was 19.38. This showed a decrease in stress scores by 15.7%. The mean scores were then sent through a program to create a t-test to determine significance of the scores.

Table 4

t-Test demonstrating differences between pre and post survey

t-Test: Paired Two Sample for Means

	<i>PreSurvey</i>	<i>PostSurvey</i>
Mean	2.297	1.938
Variance	0.28897889	0.13177333
Observations	10	10
Pearson Correlation	0.89584578	
Hypothesized Mean Difference	0	
df	9	
t Stat	4.256917	
P(T<=t) one-tail	0.00106038	
t Critical one-tail	1.83311293	
P(T<=t) two-tail	0.00212075	
t Critical two-tail	2.26215716	

Cronbach's Alpha was used to determine the internal consistency of this modified PSS-10, resulting in a score of 0.895. Scores closer to 1 denote higher internal consistency and reliability, though 0.7 is commonly used as a benchmark value for this coefficient (Frost, 2019).

Discussion

Summary with Key Findings

The global aim of this quality improvement project was to reduce the stress experienced by the PCT upon admission to home hospice. The specific aim was to decrease participant reported stress by 30% by July, 2023 by simplifying the way information is provided to the PCT in an effective manner that would increase comprehension by decreasing the reading skills needed to understand the material. Many PCTs reported being overloaded with information in different locations, and that it was easy to lose parts of or open the wrong pamphlet when they were looking for specific information. Following the intervention, participants mentioned it was easier to have a packet of information that was separate from all the paperwork in the admission folder, because they felt more comfortable sharing it with other family members without the added worry of the paperwork being damaged or misplaced.

Between the pre- and post-surveys, there were improvements in stress levels self-reported by the participants, particularly in areas regarding unexpected events and the ability to cope with home hospice. Question 2 regarding the feelings of being unable to control the important things in life had the largest difference in the scores, the mean score decreasing from 2.85 to 2. This question had to do with controlling important things in life. This change could have been due to the simplified explanation regarding the availability of respite care, volunteer services, homemaker services, and resources. By providing further explanations regarding the progression of the dying process, participants were able to prepare themselves for the coming loss and take advantage of the time they had with their loved ones. Confidence providing care increased. (mean = 2.51 to 2.14), where control over stressors also increased (mean = 2.90 to 2.42).

Some strengths of this project include the delivery process. By giving the pamphlet in person, it allowed for the PCT to understand they have help from across the spectrum of care, and from every individual in the home hospice program. In-person delivery also allowed for the

PCT to voice questions, concerns, and requests for aid, education, and support. By using the PDSA framework, verbal reports and physical observations were used to create the intervention, study the results, and plan for future studies and interventions that may be done in the future.

Interpretation

The data collected from these pre- and post-surveys suggested the delivery of timely and simple home hospice education can reduce the perceived stress the PCT experiences in regard to home care. Prior to the intervention, various individuals on different PCTs verbally reported feeling overwhelmed with the information provided and that they wished all the information was in one place. Others reported feeling added stress because they did not understand the medical terms being used. By simplifying the language through the Flesch-Kincaid readability scale and creating ways to explain medication administration, wound care, and team collaboration, stress due to education or understanding was lessened.

Limitations

A limitation of this initiative was the lack of diversity in the sample size. Because the sample was small and homogenous, the findings cannot be applied to a larger, more diverse population thus is not generalizable. The sample was homogeneous due to the patients seen in the home care setting of the counties served by the hospice facility, likely due to the white majority population in New Hampshire. In the future, it may be pertinent to create a pamphlet that can be used by various home hospice organizations across New Hampshire and other states to broaden demographics for further research and generalizability. These findings also would not be applicable to other areas of health care, such as inpatient education due to the differences in care standards and staff availability.

There were multiple instances of bias that may have occurred, including recall bias due to the pre- and post-survey format of the intervention, and survey bias, where the participants may have reported decreased stress because they knew that was the goal of the informational packet. The final bias that proved to be a large limitation of this study was non-response bias, and this may have been for a variety of reasons, such as disinterest, a lack of understanding how to access the QR codes, or a lack of time to complete the surveys. A large number of participants did not respond to either survey, and some of those who started the pre-survey did not complete the post-survey, so they were not included in the final participant numbers. The non-response bias was originally going to be minimized by beginning the intervention at a much earlier date to provide more time for feedback, but due to scheduling issues and setbacks getting approval, the window of time for the intervention was cut short. Internal validity was strong, as evidenced by Cronbach's alpha, seen in the results section.

If this intervention was to be carried out over a longer period of time, more PDSA cycles would have been completed after receiving feedback. Had this have happened, more areas could have been included in the deliverable, such as more effective coping methods that may help to decrease stress and where participants felt the packet was most and least effective. Following feedback, the packet would have been adjusted and reprinted to continue decreasing stress in the home care setting.

Conclusion

Admission to home hospice is a distressing time for many individuals, whether they have had former experience with hospice care or not. By giving education in a consolidated and simplified form that could be easily understood by most people, a better understanding home hospice care and what to do in situations regarding medication administration, comfort, and

coping were achieved, likely causing the reported decrease in perceived stress. This intervention was useful in determining simple ways to decrease stress in the PCT that may grow to be something more serious, such as caregiver burnout. It is a sustainable intervention, as the majority of the information provided was already given in the standard admission packet, but this intervention was financially more reasonable, as it detracts the need for other pamphlets that were simplified and included into the single intervention.

When considering other areas of healthcare, this method of simplifying and condensing information could prove useful in the palliative home care setting. It could also be used by individuals such as in the AIM Team to provide meaningful hospice education to PCTs that may be considering hospice, but are not ready to make the transition yet. By providing this information at an earlier time, it may decrease stress, but also result in more informed decisions being made that may encourage earlier hospice admissions, thus increasing the quality of life for those under the care of the providers.

Should this be used for further study, it would be pertinent to examine its effects among a more diverse population (both in age ranges and ethnicities) of a larger sample size to make the information generalizable. In the next rounds of the PDSA cycle, it is recommended to add more questions to the surveys that may delve deeper into the root of the stressors and how professional staff may help to alleviate them. Not only could an intervention like this decrease the stress felt by the PCTs, but if consistently utilized by organizations, over time it could increase satisfaction ratings.

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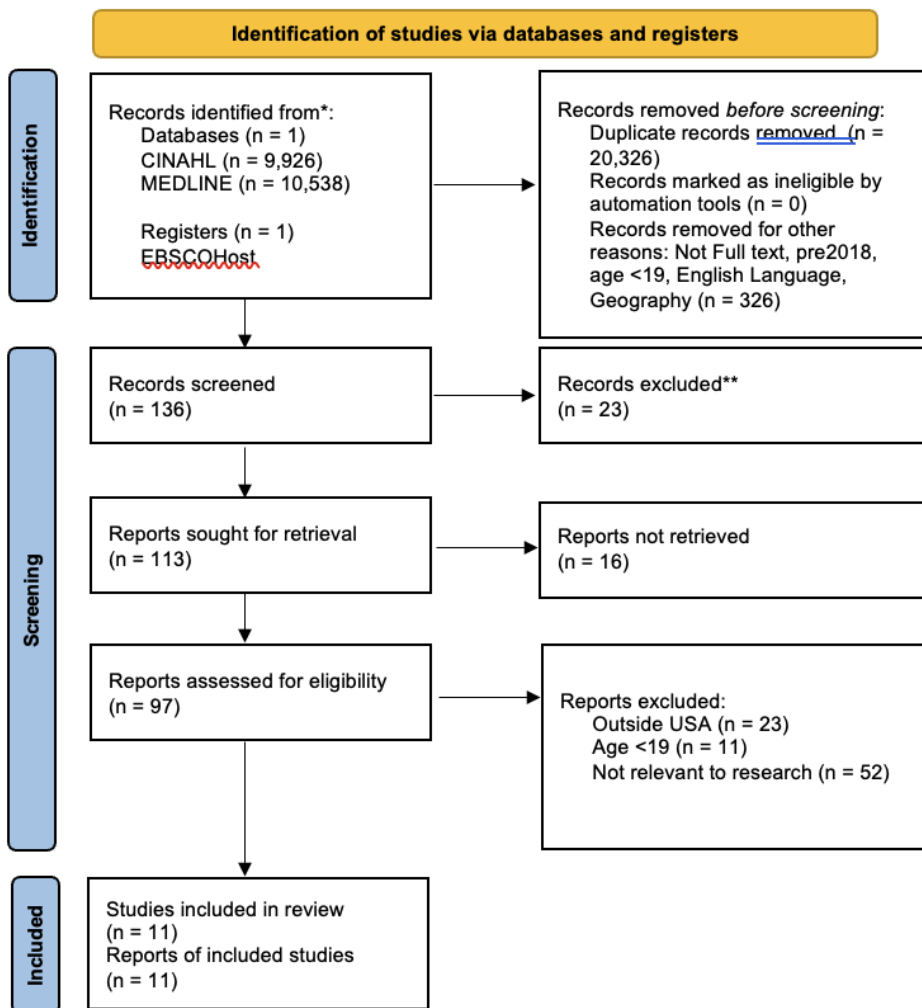
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Appendix

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only

x



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

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